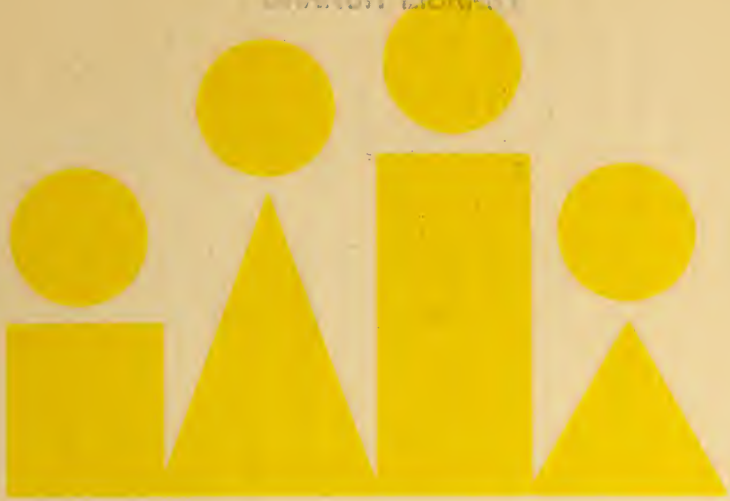

# DEVELOPMENTAL REVIEW IN THE EPSDT PROGRAM





pared by

U.S. Department of Health, Education, and Welfare
HEALTH CARE FINANCING ADMINISTRATION
in cooperation with
THE AMERICAN ASSOCIATION OF
PSYCHIATRIC SERVICES FOR CHILDREN, INC.

# DEVELOPMENTAL REVIEW

# in the

# EARLY and PERIODIC SCREENING, DIAGNOSIS and TREATMENT PROGRAM

## FINAL REPORT

April, 1977

This report is made pursuant to HEW contract no.
SRS 500–76–0510

Prepared by
The American Association of Psychiatric Services for Children, Inc.

U.S. DEPARTMENT OF HEALTH, EDUCATION, AND WELFARE
Health Care Financing Administration
The Medicaid Bureau
(HCFA) 77-24537

## ACKNOWLEDGEMENTS

This report was prepared by Dorothy S. Huntington, Ph.D. It represents a synthesis of material supplied by various position papers, conference proceedings, and helpful suggestions made by those who responded to the initial draft of the report. The American Association of Psychiatric Services for Children wishes to express its gratitude to all of those who are listed on the following page who generously gave of their time and counsel.

We must be held solely responsible for all errors of omission or commission. Nevertheless this project could never have been accomplished without the tireless and invaluable participation of **Dorothy S. Huntington,** Ph.D., Chief, Child and Family Services, Community Mental Health Center, Peninsula Hospital and Medical Center, Burlingame, California, who participated in the original planning for the project, synthesized one of the original working papers, chaired the conference itself, and prepared all versions of this report. Special thanks also must go to the following people who authored the original working papers: **Allan G. Barclay,** Ph.D., **Thomas Coleman,** M.D., **Anne-Marie Foltz,** M.P.H., M. Phil., **Frances Degan Horowitz,** Ph.D., **L. Wendell Rivers,** Ph.D., and to **Jane R. Mercer,** Ph.D., from whose research and publications the sixth working paper was synthesized.

American Association of Psychiatric Services for Children Conference on Developmental Screening and Assessment held in San Diego, California February 10-12, 1977

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# EXECUTIVE SUMMARY

## I. PROLOGUE

Developmental assessment is an extraordinarily complex topic, but one which holds enormous promise for all children. Attempting to make recommendations about developmental assessment perhaps approaches the level of a Herculean task.

> In view of the work ahead of this group I am reminded of a story which appeared in the **Washington Post** supplement. The story was set on an ancient Roman galley and the Hortator, the one who bangs on the drum to keep oarsmen in cadence, says—"I got some good news and some bad news! You all get steaks tonight!" "Yea!" "Yea!" from the rowing benches. "And now the bad—the Captain wants to go water skiing tomorrow!" I get the feeling that the organizers of this conference are *avid* water skiers. (Hurt, 1974)

The Early and Periodic Screening, Diagnosis and Treatment Program (EPSDT) became a mandated service under the Medicaid Program through an amendment in 1967 to the Social Security Act, Title XIX, Section 1905 (a) (4) (B). Effective July 1, 1969, it required

> . . . such early and periodic screening and diagnosis of individuals who are eligible under the plan or are under the age of 21 to ascertain their physical and mental defects, and such health care, treatment, and other measures to correct or ameliorate defects and chronic conditions discovered thereby as may be provided in regulations of the Secretary.

We recommend that a major shift in emphasis and conceptualization be made with reference to EPSDT and developmental issues. These recommendations flow from a

consideration of a wide variety of salient points, the most basic of which is that development is not a disease which yields a judgment of present or absent. We are basically concerned with the concept of competence—how well has a child met, and how well does he now meet, the expectations implicitly and explicitly set by his society for an individual of his/her age and sex group.

The legislation authorizing EPSDT makes it national policy that the development of our children, our future citizens, be safeguarded so as to insure that each child reaches maturity functioning at a maximum level of development. This goal is more than the finding, the study, and the treatment of disease. The guardianship of the health of children is in the national interest as well as in the interest of the individuals; this is the essence of EPSDT.

Parents must be accepted as full partners with the professionals who plan and staff the services provided for children. If responsible parenthood is to be encouraged, then parental involvement must be fostered. No single department or unit of the Federal government nor of local governments, and no single profession, has "the key" alone to promoting childrens' development. Only through coordinated service delivery as proposed herein is this possible.

We must develop a system of health care that treats the person rather than the disease or dysfunction. We are urging the development of a system for the protection of child development, a system of developmental review.

No single test or instrument is recommended because none could possibly be used for the adequate accomplishment of a developmental review for all ages and functions. Each review must include multiple assessment procedures tied to the age of the child and the dimensions to be assessed.

Any system of review must be predicated upon parental and child involvement in the review.

Any review must be oriented to the discovery of developmental strengths as well as weaknesses, not to the exclusive search to rule in or rule out pathology.

Every attempt must be made to voluntarily engage and utilize parents in the entire process of continuity of care and developmental review.

We recommend this system for all our child citizens. We encourage the recognition that the current law as specifically written is inadequate, undesirable and almost impossible to implement, but if the welfare of children is the goal, this proposed system should be set in its place.

There must be an integration into the EPSDT program of payment for all services which are needed by a child or family as a result of developmental review, including special education costs.

Our basic message is that developmental review is much more complicated than it appears when it is labeled "developmental screening" but yet the system of developmental review holds out enormous promise. We are, in this program, at a point of crisis; it is instructive to note that the word crisis in Chinese calligraphy is the blending of the two symbols for danger and opportunity.

National and individual interests may or may not coincide in a screening operation; indeed they may sometimes be in conflict, but they will always coincide with regard to the guardianship of the development of our future citizens. Thus the issues are more complicated and more relevant to both national and individual interests than the critical incident style of assaying or analyzing for specific fixable defects. The issues are more in the realm of a periodic review of a process, that of development. They are relevant to all children. Further, they are more relevant to a synthesis of function, supports, and developmental needs than to analysis and fragmentation.

Once this departure from the former conceptual model is accepted, we can go on to the details. To state it most concretely, we believe with reference to developmental and psychological issues, that the national mandate for EPSDT may better be stated by a change in name to EPRDT; the "R" representing a developmental review rather than a screen. The function of the review is to assess the ways in which development is occuring, the form that it is taking.

It then follows that national and individual needs and priorities will determine the processes to be used for the review and the resources available. The process and the resources will in turn determine the level of review, the ages served, and the backup treatments to be made available. It is at this final level of conceptualization where specific methods of review

may be suggested, and specific ways of delivering services involved in this review may be proposed.

It is apparent that the present legislative language, which states that there shall be screening ". . . for mental defect . . .", is clearly inappropriate. The proper emphasis, in our opinion, is upon a process of developmental review, with the object being to identify strengths and competencies as well as weaknesses and defects.

It is assumed that the legislative intent of the EPSDT Program was to establish a national policy such that the development of the child be safeguarded in order to insure that, as with any other national resource, the resource is available to the nation. To that end, it is assumed that the *raison d' etre* for the program must be the husbanding of our child resources, from both a humanitarian and an economic point of view, and that the EPSDT Program must not have a narrow focus upon defect, but must look as well toward the optimization of the development of the child.

The policy surrounding the fuller implementation and development of the Early and Periodic Screening, Diagnosis and Treatment Program should be based on three principles:

1. **a national commitment to the well-being of all children**
2. **a fostering of parental involvement**
3. **a pooling of professional and parental knowledge.**

A policy for children must give practical recognition to the fact that they are the citizens of the future. Their development determines the fabric of tomorrow's society. At a time when resources are limited, there is a case for concentrating them where they can do the most good, in the area of well-being of children and families.

## II. RECOMMENDATIONS

A. Our first recommendation is that the EPSDT mandate be broadened to apply to all children in this country so that a

system of developmental review and protection might be planned for comprehensive implementation. It is also urged that funds be made available for the development of health care resources, including manpower, facilities, and research and development.

B. In the interest of pooling resources, consolidating efforts, and effecting maximum impact, we recommend that the currently existing extensive overlap in functions and goals of existing Federal programs be eliminated. The Maternal and Child Health program, the Education for All Handicapped Children Act (PL 94–142), and other programs sponsored by NIMH, NICCHD, BEH and OCD/Children's Bureau have significant duplication of effort with EPSDT; a thorough review of existing programs and agencies serving children should be undertaken, with the goal of effecting such mergers as would improve our services to children and reduce duplication.

C. The establishment of an EPSDT Coordinating Office at the local level is recommended; the function of this local coordinator will be to insure that the review, referral, treatment, information dissemination and follow-up resources of the community be utilized in carrying out the goals of the "merged", coordinated EPSDT program. Also recommended is the establishment of EPSDT Community Coordinating Councils to include the schools and all service agencies, as well as representatives of parents and service providers.

D. These support systems are being recommended in order to enable and facilitate planning on the local level; identification of gaps and needs in the service resources; coordination and stimulation of services relevant to achieving goals of EPSDT, and cooperation and contribution to the external evaluation of EPSDT. We clearly are recommending multiple models of service delivery depending on the characteristics of individuals and agencies available as support systems.

E. We recommend a new approach to the discovery of "handicapping conditions" or "mental defects". Developmental review is seen as the first step in engaging children and parents in an ongoing concern with their health and well-being. We see it as a way of promoting strengths, as a way of engaging parents with their children, of strengthening these parent/child ties, and of reducing the anxiety so prevalent in our society today regarding issues in parenting and child rearing. This is a true system of health care versus specific medical care.

F. As the individual with primary responsibility for the care of the child and for the facilitation of development, it is vital that the parent or other caregiver be meaningfully involved in the process of developmental review.

G. Such developmental review should, to the maximum extent possible, avoid coercion such as mandating that the developmental review be a condition for a survival need such as a welfare payment. Vigorous efforts should be made to insure voluntary participation by the parent in the developmental review.

H. Such developmental review should, to the maximum extent possible, provide significant benefit from participation, in the form of a better understanding of the child, with the aim being to provide assistance to the parent in coping with developmental issues, and facilitating future development.

I. Such developmental review should, to the maximum extent possible, recognize, respect and incorporate ethnic, cultural, social and linguistic differences that exist in a pluralistic and culturally and ethnically diverse nation such as the United States.

In a free, pluralistic society, there are clear boundaries on the scope of legitimate inquiry into personal and familial concerns. Therefore a mass government financed screening program should be limited to:

1) those measures of organic functioning and basic, adaptive coping skills which enjoy a high degree of consensus within the health professions and effected communities, and

2) those behavioral factors especially associated with learning, language and speech development, motor skills and perceptual abilities.

Specific assessment of emotional and behavioral adjustment and parent/child interactions should be left to parental initiative and sensitive clinical observation (Stage Three as herein proposed.)

As an integral part of the initial outreach phase of a developmental review effort, parents should be provided in the language most appropriate to them, a written description of the nature and purpose of the proposed procedures, including adequate assurances of its quality, confidentiality and bene-

fits to the child and family. At the time the parent personally appears, he or she should be verbally informed of the nature and purpose of all developmental review procedures, and should be notified that selective participation is possible. A refusal to authorize any given procedure must not jeopardize the child's access to any other aspects of the program. Parental consent should then be obtained for each procedure and for any proposed transfer of records or information upon completion of the developmental review. Each child being served should be informed of the nature and purposes of the procedures and their results to the maximum extent possible consistent with his or her level of intellectual and emotional maturity.

Any transfer of developmental information between and among systems is recommended *only* when the information would be helpful in identifying those conditions under which a child functions best, so as to enable, for example, optimal school placement. It is our recommendations that only diagnostic (Stage Three) information that is pertinent to educational prescription for the child be communicated to the schools, subject always to informed parental consent.

J. It is strongly recommended that no single instrument for development assessment be mandated nationally. There is no one single instrument, inventory or assessment tool that is totally satisfactory.

Any instruments, materials and methods for developmental review within the EPSDT program must be normed for the minority group with whom they are to be used. They must also be interpreted by persons who are familiar with the economic and cultural background of the populations being assessed.

K. The system for developmental review must be clearly recognized as a system, not a piecemeal approach.

We recommend research and development or demonstration projects to develop measurement and evaluation standards appropriate to the assessment of children and their environments. There should also be research into the methodology of developmental review with emphasis on a variety of assumptions and theories related to age and ethnicity.

There must be the development of strategies for the simultaneous selection of measurement variables and the

identification of program needs, for the establishment of research, development and evaluation priorities. There must be an emphasis on the overlap between research and consumer priorities. In addition, there must be provision for taking into account family needs and values in the conceptualization of measurement related problems, and in the development, selection and application of any measurement or other instruments. Parents and those directly responsible for the welfare of the children must be involved in all decision making processes in this area.

The focus in interpretations of assessment must always be on individual differences that will lead to appropriate intervention for each specific child, as opposed to a focus on group difference and comparisons.

There should be a collection of multi-measure, multi-domain, multi-function measures from which instruments may be selected at a local level, by local option for Stage Two and Stage Three reviews.

L. Adequate developmental review would include factors from these areas:

1) biological dimensions

2) psychological dimensions

3) family dimensions

4) environmental/social/cultural elements

M. The review should be carried out in three stages:

1) Stage One

a. The biological dimensions would be reviewed within the framework of the pediatric physical examination, which would be expanded to include an opportunity for the child and family to discuss, if they so wish, any stresses or problems with which they would like help, or to identify strengths and support systems that could be engaged to provide for furthering development.

b. An assessment of the child's functioning would be done based upon the parents' report in the areas of development of skills and emotional and behavioral status.

2) Stage Two

Direct observation of the child's functioning, utilizing a variety of broader developmental screening inventories or instruments.

3) Stage Three

This stage of developmental review would include detailed aspects of the four domains: biological, psychological, family, and environmental/social cultural. The psychological domain would include a wide variety of functions—cognitive development, coping strategies, social development, emotional development, language and speech development, auditory perception, visual perception and physical functions.

This extensive review of a child's development at Stage Three, this clinical assessment, must be done with great clinical sensitivity by people highly skilled both in child development and in working with parents.

N. It is clearly necessary that we develop appropriate instruments in order that all stages of developmental review be carried out most adequately. There is not at the present time a single, universally acceptable tool for developmental review although there is a multiplicity of such instruments appropriate in differing situations and for differing developmental problems.

It is strongly recommended that the Medical Services Administration take a leadership role in establishing task forces and demonstration projects to develop further review procedures relative to acceptability, standardization norms, instrument reliability, instrument validity, concurrent validity, use by paraprofessionals, cost effectiveness and availability. In developing parent questionnaires, concerning their child's development, it is obvious that the questionnaires must not be trivial, must have developmental implications, and must have cross-cultural validity.

O. It is also recommended that a separate task force be appointed to supply a list of tests currently available, with information on how well they meet these criteria (section N above) of appropriateness, and in what areas of psychological, family and environmental review.

In connection with this, it is strongly recommended that there be constructive use made of data already available from past projects such as the collaborative studies, in order that we may become much more sophisticated about issues of longitudinal prediction.

After two years, no standardized procedure should be utilized in the program until it has been approved pursuant to regulations adopted by the Secretary. In the interim period, this Task Force shall review standardized procedures currently in use to determine their compliance with these above mentioned criteria, and shall recommend appropriate regulations to the Secretary.

P. It is recommended that a separate task force be developed that would collate and make available to local communities the varying models of parent based "treatment" programs that have been developed, and also make available the wealth of parent education materials that currently exist in many scattered places. This particular use of parent education materials holds within it a truly exciting and innovative approach to health care in this country.

Q. Any developmental review system initiated under EPSDT should clearly reflect the important distinction between the disease recognition and prevention model, and the cultural diversity model. Screening may legitimately utilize the "disease model" during the years of infancy and early childhood development when the child's primary social group is the family; in doing so, however, developmental review must focus primarily on the child's "physiological" development. Conversely, as children enter the mandated school system, when their behavior is evaluated with reference to the expectations of the social group, developmental assessment necessarily encompasses behavioral measures, and policies must therefore be formulated within the normative framework of the "cultural diversity" model.

R. It is recommended that specific guidelines concerning program evaluation be developed by a task force of experts who have specific competency in this area. We caution that this must be done quite soon, so that elements considered essential to proper program evaluation be included in those programs now in the process of implementation. Evaluation of EPSDT should be done in relation to specific, predetermined process and outcome measurements.

One of the most important issues in evaluation must be the inclusion of a search for possible positive and negative side effects of any system of developmental review on children and their families. This would include an investigation of any problems associated with potential "labelling" as a consequence of the administration and implementation of any of the aspects of developmental review herein recommended.

Research must be set up to provide answers to cost issues, and to develop appropriate systems for collection of data to estimate costs and benefits of publicly financed child health programs.

S. The proper implementation of EPSDT across the country will require the development of training programs in order to increase the sophistication of professionals in the area of normal development, developmental review, and opportunities for the developmental protection of children. Therefore, we recommend that there be an expansion of existing sources of funding so that training programs necessary for existing professionals who will contribute to the achievement of the goals of EPSDT be made available. We include in the group of eligible professionals: physicians, nurses, teachers, psychologists, social workers, school counselors, and speech pathologists and audiologists. Training programs should be carried out by existing accredited training resources and institutions (for example, universities, state colleges, community colleges). Training could be offered in the form of workshops, courses, seminars, and inservice training programs. We also recommend that training funds for paraprofessional personnel be made available on the assumption that Stage One and perhaps Stage Two of the developmental review process will be carried out by such personnel, and on the assumption that a great deal of the parent support work will also be carried out ultimately by paraprofessionals.

We urge increased effort to sensitize health professionals to the problems of parents, to the issues of ethnic diversity within this pluralistic socety, and we urge that health professionals be trained to offer increased support and counseling to all families.

In order to achieve the goals of EPSDT, special resources for developmental review need to be created to supplement the kinds of assessments typically done by physicians. The

nature of these special resources are largely specially trained personnel. Such personnel should have extensive skills in using developmental evaluation techniques, should know something about the arena in which physicians operate and similarly should have some familiarity with the nature and requirements of effective educational settings. They must also know about parents, about families, their ethnic and economic diversity and the realities in which they live in our society.

# RATIONALE AND ELABORATION

## 1. What is Developmental Review?

It is evident that the development of a child is a process, requiring periodic review to insure that development is proceeding adequately. Thus the term "screening", with its connotation of searching for a defect, is less appropriate than is the term "developmental review" which implies a process orientation rather than a simple cross-sectional view. While it may be difficult to change the present legislative language, it is urged that the process of developmental review be strongly encouraged, and that the concept of developmental screening, which is more appropriate to medical or disease oriented conceptual models, be avoided.

Developmental review in the context of a health program has three goals:

1. The promotion of strengths of a child and family to cope with the various tasks of living;
2. The prevention of specific developmental disabilities;
3. Early case finding;

At this time we are recommending an entire reconceptualization of developmental assessment within the EPSDT program. The elements of "Operation Rethink" involve a reassessment of what "mental defects" are; what mental health and development are; the role of the family in child development; the orientation of a screening, diagnosis and treatment program around the integration of the family within the system; and finally, how one produces developmental gains via various support systems.

Under the proposed system of conceptualization there is no way in this field to identify precise tests to distinguish between "normal" and "abnormal" children; there are dozens of

crucial functions subsumed under the concept of development, since development is not one *thing*. Developmental review would thus consist of an assessment of these functions rather than the specific diagnosis of *a* condition. A functional assessment, a profile of strengths and weaknesses, or assets and liabilities, describes the transactions between the child and the world around him in terms of the tasks asked of him and the people significant to this life, in the context of the particular setting in which the child is found and at the particular time of every developmental review. The outline of assets and liabilities, strengths and weaknesses, is clearly not related solely to the functioning of the child but is defined specifically in relation to the expectations of the important people and institutions in a child's life: family, school, friends, whatever is uniquely and individually important to any one particular child.

The effects of early life experiences as well as the effects of recent experiences such as a divorce in the family, the loss of a parent or other significant person via death, situational issues such as a fear of the procedures, all have a powerful effect on the ability of a child to demonstrate the quality of his functioning during any specific review. Developmental review would thus assume that the child and his environment (including significant caregivers) are a unit and are not divisible. One does not exist without the other. One cannot be reviewed adequately without consideration of the other. Developmental review concerns itself with what goes on between the child and this environment on the biological, psychological, social and cultural levels.

It is just as foolish to search for a single method of observing a child's development as it is to tell a physician that he must use only one method (using a stethoscope versus using a thermometer versus visual inspection, for example) to complete an entire physical examination. However, it is obvious that a combination of methods will allow the observation of a set of significant functions. It must be stressed repeatedly that development is not a disease which yields a judgment of present or absent. We are basically concerned with the concept of competence—how well has this child met, and how well does he now meet, the expectations implicitly and explicitly set by his society for an individual of his/her age and sex group?

This approach raises a host of questions and issues. To be addressed are such considerations as the difference between medical and psychological screening, diagnosis and treatment; the difference between an individual problem of a child and the matrix of social problems that might be reflected in a child. Also to be addressed are issues such as primary prevention as the detection of disease in non-symptomatic persons versus the newer concept of promoting strengths and promoting health. One must also consider health care in general versus medical care; this is a particularly prominent issue since EPSDT is essentially a medical care system.

With all the foregoing in mind, we recommend a new approach to the discovery of "handicapping conditions" or "mental defects". We do not see developmental screening only as a quick, simple procedure to identify those in need of further study but rather we see it as the first step in a way of engaging children and parents in an ongoing concern with their health and well being. We see it as a way of promoting strengths, as a way of engaging parents with their children, of strengthening these parent/child ties and of reducing the anxiety so prevalent in our society today regarding issues of parenting and child rearing. This is a true system of health care versus specific medical care.

We run the danger within developmental review of the fallacy of misplaced concreteness. There has been in the past an almost obsessive concern with the number of false positives and false negatives that each specific test yields. This is not truly the issue; the issue is what a parent thinks of his child, how he perceives the child, and how the child thinks of himself/herself. In addition it must be noted that this obsessive concern makes it sound as if there were a magical treatment available once the case is "diagnosed" according to this single all powerful instrument. That this is not the case will be reviewed in the following section. Again, we see the screening process and the diagnostic process themselves as the first order "treatment", through the engagement process by helping a parent think about the child's emotional and developmental status in a new way, in the context of a relationship with a helping person, a health professional in the broadest sense who is interested, who cares, is supportive and listens.

## Engaging the Parents

In order to accomplish the goal of assessing a child's growth, strengths and weaknesses, one must as a prerequisite engage the cooperation of his parent or caregiver. Although logical, this process is at times ignored. This leaves the parent non-engaged, virtually sabotaging any cooperative effort on the part of an "outsider" to assess the function of a child. In actual practice this also leads to a very low number of return visits for diagnosis and treatment, when referral is made without parental engagement.

The parent is the only observer of a child's rate of growth from birth until school age. Health professionals are not predictably involved in any consistent manner. When the child enters school, a new observer is identified, the teacher. Therefore, the parent must be engaged early in the infant's life in order to utilize his observational skills in developmental review. The teacher likewise can be a valuable adjunct with parental approval to give information about the rate of growth of the child. The exclusion, however, of the parent when the teacher's observations are sought, can lead once again into a sabotage of future attempts to assess the child.

All parents, whether single or "coupled", have some fears about outsiders observing their child, and indirectly their "parenting". These fears can be stated as a "fear of labeling: good parent–bad parent" with a further extension of such, "good child–bad, defective child". Since parenting is frequently filled with ambivalent feelings of whether or not the "effort is enough", the fear of intrusion from an outsider is constant. On the other hand, the assistance and clarification of areas of concern are greatly welcomed and invited.

A further fear is that if any defect is discovered, there will be in fact no assistance or treatment for the correction of such. With these considerations in mind, the following suggestions for engagement are made:

1. Every attempt should be made to voluntarily engage the parents and the child. Coercion by mandating an exam or by attaching the exam to a survival need (money from welfare), immediately raises resistance and anger.

2. In order to have the parents cooperate, they must understand the benefits of participation. A model allowing for parents to evaluate the child first (parental inventory) with the opportunity to discuss areas of concerns as well as strengths, allows parents to look forward to assistance, rather than to fear "criticism".

3. The process of engagement should follow the stages of the parents' assessment of their child's development, and the parents' participation with a health worker to talk about areas of concern. (This also offers the opportunity for direct observation.) It would, in addition, be important at this stage to have a health worker who is bicultural and bilingual.

4. Although there may be a period of time from the initial contact to the definitive "diagnosis", the process of engagement with parents will enable the review to proceed. The failure to follow this engagement process could negate the opportunity to proceed to the desirable goals of treatment, remediation and facilitation of growth and development.

5, The definitive diagnosis, even though confirmed by criteria and norms, must be shared with the parents by a health professional with high sensitivity, expertise and knowledge of the parents.

6. The earlier the engagement process takes place, the easier it will be to have an accurate assessment of the child. Once rapport has been established at an early age, ideally birth, the review can take place with ease.

## 2. Some Considerations in Developmental Screening, Diagnosis and Treatment: Strengths versus Weaknesses

We must think very clearly about the implications of the difference in concept between screening oriented to promotion of strengths and prevention of disorders, and screening oriented to defects, damage, dysfunction, illnesses and weak-

nesses. We select tests partially on the basis of what use is going to be made of the results. The emphasis on defects and weaknesses leads to many ethical, social and psychological problems. In order to be concerned with success rather than failure, we need to establish a non-pathological model. As Brazelton (1976) has said,

> A new model is needed in pediatrics—a non-pathological model. With such a model that identifies the strengths of parents and children, the pediatrician would present himself as an advocate rather than a labeler. The Hawthorn effect would be great—expectations that they would succeed might reinforce their sense of dignity, of their own coping capacities, instead of the kind of expectancy to fail which, too often, they find now.

This viewpoint is especially important if we are to screen for mental retardation where, without ignoring pathology, we must be concerned with positive adaptive, coping capacities and not just with "defective" scores or failures on formal I.Q. testing.

## The Nature of Intelligence and the Concept of Development

The traditional assumption is that mental retardation is a chronic handicap that exists in a person as an individual characteristic, unrelated to the circumstances of that individual's life. There are two models, then, of retardation: the pathological and the statistical. The pathological model is based on a disease model that views mental retardation as a biological dysfunction typified by particular biological symptoms. The statistical models states that a person is abnormal if he falls into the tails of the statistical distribution of the population on whatever measure is being used for diagnosis. Both models imply a relatively simple conception of a developmentally constant and pervasive factor of general intelligence, yet this conception is no longer tenable as a model for "mental" development.

Intelligence is clearly a matter of basic endowment, health status, environmental expectations and experience, learning and definition. The pathological model fails when one refers to psychological functions: development is not a disease that

yields a judgment of present or absent. There is an enormously wide range of what is "normal" or "average" in developmental processes, and an equally wide range in the variant rates at which different functions develop in different children. One frequently wishes that this were not so, but it must be stressed that "development is not a single unfolding of more complicated behavior from infancy to maturity, but a process of learning and interaction." (Boelsche, 1969)

## The Model of Medical Screening versus Developmental Assessment

The nature of developmental phenomena discussed above leads to very different models of screening and assessment.

Medical screening is a sophisticated concept; such screening is usually simple, quick, capable of "pass or fail" interpretation; it is applied once to each subject to minimize non-cooperation, and lends itself to evaluation in terms of sensitivity, specificity and repeatability.

Developmental assessment of psychological functions on the other hand, is a clinical procedure to which "pass or fail" interpretation should not be applied, repeated examinations are essential and it is not amenable to detailed quantitative evaluation. (Rogers, 1971). The essentially clinical nature of developmental assessment must never be overlooked; screening cannot be a "one-shot" attempt on a parameter that is developmental.

Developmental assessment involves a description of the child's adaptive functioning in the major areas of development of skills (motor, language, self-help, etc.) and adjustment, including behavioral and emotional characteristics. Such description of development and adjustment may be based on parental report, clinical observation and possibly direct testing of the child.

Preliminary interpretation of functioning in relation to the expectable range for children of the same age, sex and cultural group then defines a developmental profile of the child's strengths and weaknesses. This developmental profile may be used to define needs for further evaluation or other intervention.

There are marked differences in the personnel required, also, for medical and developmental screening: for medical screening tests, suitable training in procedure is necessary but no previous clinical experience is necessary or even desirable. Developmental assessment, on the other hand, should only be performed by personnel having broad experience in the children of the age being assessed, and having specific training and experience in the field.

If one uses the analogy of screening oranges for size as an appropriate one for medical screening, then it is easy to see that the appropriate method for screening is the use of some sort of size sorting equipment—screens with progressively finer mesh.

> Of course there may be numerous other standard characteristics against which any given orange must be assessed, such as juiciness, sweetness, resistance to bruising, color, thickness of skin, peeling ease, general esthetic appearance, etc. Some of these characteristics are more difficult to mechanically screen and assess than others, thus requiring the informed, relatively subjective assessment of trained interpreters to differentiate and classify them. (Meier, 1973)

This seems an appropriate analogy to developmental screening and assessment. Because we use the same word—"screening"—we seem to have confused the concepts of medical screening for the presence or absence of disease with developmental screening, which might more appropriately be called review of developmental status.

The distinctions between the two models complicate the generation of a comprehensive, nation-wide screening system. The dangers of over-generalizing a model which may be relatively satisfactory in one realm to other, inappropriate realms cannot be overstressed.

### State Behavior

The physiological and psychological state of the infant and child at the time of testing, that is, the degree of wakefulness, alertness, anxiety and attention is an important confounding factor in all screening and assessment efforts and frequently has been overlooked. Thus it is possible that a low score on

some screening or assessment procedures may not be a function of some deficiency, but rather a function of the child being in a state inappropriate for that assessment at the time. The issue of the strange surroundings must also be carefully considered in relation to the child's degree of comfort, and therefore test-taking ability.

**Developmental Issues**

Screening cannot be a one-shot testing session on a parameter that is developmental. There is a great deal of misunderstanding about developmental issues in children, and about the constant change in their developmental capacities. In addition, infants and very young children are difficult to screen and assess definitively because of the wide range of normal inter-and intra-individual variations as they rapidly grow and develop.

**Lack of Predictive Validity**

Developmental screening in the traditional sense cannot be used to predict future potential, because of the nature of "intelligence", because of the limited number of items on such screening devices, and because of the difficulty of standardization using different ethnic, socio-economic and educational backgrounds of children and families. Such procedures should be used only as observational descriptions, by thoroughly trained examiners, which would then lead to plans for educational and remedial intervention for each child. Stability of intellectual functions is very probably in large part a function of environmental stability, and in no way may one predict how an individual might do when the environment is radically modified toward greater enrichment or deprivation. The predictive validity of developmental screening devices is thus very poor, based on issues of environmental stimulation or interference.

**Problems of Personnel**

Since children of pre-school age are frequently shy with strangers, in a new setting and with strange tasks, the skill of

the examiners is an especially important issue. In many cases, bilingual competence will be crucial, as will be a thorough knowledge of the expectations of each ethnic group for their children. Programs to develop personnel with such skills, and to train, re-train, do periodic proficiency checks and constant supervision are extremely costly.

### The "Treatment"/intervention System

The basic question of having a detection system when no "treatment" is available must be faced. If screening and then full scale assessment do not guide some form of "teaching" process or intervention system, why do it? Improvement in the health status of poor children requires meeting a large volume of unmet need for health care as well as changes in environmental, social and other factors that affect health status, but are outside the scope of a reimbursement and support system related solely to health services delivery. This is a crucial point, particularly in the area of "mental defects". Many developmental "defects" are social, educational or nutritional. Unfortunately the required services are not eligible for reimbursement under the current Medicaid system. The Federal appropriation for Medicaid does not include, and State Medicaid agencies do not have, funds that can be directed toward development of health care resources, whether manpower, facilities, or equipment, or toward research and demonstration efforts, specifically for the purposes of EPSDT.

When a satisfactory comprehensive developmental screening system has been field tested and thoroughly debugged, it is only useful if it plugs into practical intervention programs. The implementation of early childhood intervention through EPSDT has enormous potential for impact on the health, mental health and welfare of the entire country.

## 3. An Approach to Developmental Review

Given that the process of developmental review is more appropriate than that of screening, it becomes apparent that such developmental reviewers must, of necessity, engage the

parent or other caregiver as a significant aspect of the review process. Thus, in order to accomplish the goal of reviewing the development of the child and the concomitant strengths and weaknesses, the assistance of the parent, or other caregiver must be engaged. Any such review process must make vigorous efforts not only to engage the caregiver in the review process, but must also be alert to the psychological dynamics of the review process, such as the natural ambivalence to intrusion into the family and consequent concern about adequacy as a parent or caregiver. Any such developmental review process should, to the maximum extent possible:

1. Avoid coercion, such as mandating that the developmental review be a condition for a survival need such as a welfare payment.
2. Provide for significant benefit participation in the form of a better understanding of the child, with the aim being to provide assistance to the parent in coping with developmental problems, rather than the anticipation of criticism for inadequate parenting.
3. Recognize the ethnic, cultural, social, and linquistic differences that exist in a pluralistic and culturally and ethnically diverse nation such as the United States. The developmental review process especially the interpretation of the findings of such a review, must make a vigorous effort to insure that such differences are recognized, respected and incorporated appropriately.
4. Insure that there is adequate provision for an interpretation and review of the findings with the parent, taking into account the strength as well as the weaknesses of the child, and insuring that the interpretation is, to the maximum extent possible, of practical benefit to the child and parent in the facilitation of future development.

Thus, the process of parent "engagement" is viewed as a primary prerequisite for any adequate developmental review, and as a *sine qua non* of the adequate implementation of such a program.

**Developmental Review**

Given an extensive review of currently available materials, it is strongly recommended that no single instrument for de-

velopmental assessment be mandated nationally. There is no one single instrument, inventory, or assessment tool that is totally satisfactory. Any instruments used must meet the criteria discussed below. At the current time there is no one instrument that meets such criteria. There are a number of assessment tools that might serve as prototypes of approaches to the adequate conduct of a developmental review, and the criteria for such exemplars are discussed in the following section. It is also strongly recommended that the system of developmental review herein discussed be clearly recognized as a system for developmental review, not simply a piecemeal approach. We strongly urge that this system of review be adopted and implemented, and that appropriate guidelines and regulations be developed for its implementation.

In essence, the system of developmental review proposes that an adequate review would include factors for these areas:

1. biological dimensions
2. psychological dimensions
3. family dimensions
4. environmental/social/cultural elements.

The review should be carried out in three stages:

**Stage One**

The biological dimensions would be reviewed within the framework of the pediatric physical examination. The basic sampling from the biological domain would be conducted as set forth in the guidelines for the pediatric examination of the American Academy of Pediatrics. It is further proposed, however, that the pediatric examination be slightly expanded to include an opportunity for the child and family to discuss, if they so wish, any characteristics of the family situation that they identify as causing stress and problems, as well as to identify strengths and support systems that assist the family in its coping behaviors. Some sample questions that might be added in the course of the pediatric examination and health history are:

Who is in the family unit?

How are the key relationships functioning (parent/child, couple, child/child)?

Are there health and/or social or emotional problems that are of concern to the family?

This opening of an opportunity to review problems and assess strengths and support systems with the health personnel allows for further engagement and child/family development.

The second area to be covered in Stage One review is an assessment of the child's functioning based upon the parent's report. This would provide an opportunity for the parent, alone or in interaction with the health personnel, to comment on the child's developmental progress and on issues relating to behavioral adjustment, temperament, coping capacities and the like. This would involve two sub-sections:

1. A parent report (interview or inventory) of the child's developmental skills (motor, language, etc.) that would provide a developmental profile of the child's functioning.
2. A parental report (interview or inventory) of the child's adjustment and emotional and behavioral status.

Both of these reports may, according to local option, be developed as structured inventories which would permit review of changes over time as the child is followed in the health care system. The use of structured inventories would also allow paraprofessionals a key role in gathering this information.

**Stage Two**

On the basis of the informal observations of the person doing the health examination, and on the material from the parent questions, the parent inventory covering developmental areas and the parent inventory covering behavior, it would be decided if there were a need to refer a specific child to Stage Two. In Stage Two there would be direct structured observation of the child's functioning. This might be accomplished using a variety of broader developmental screening inventories or instruments that are currently available. Paraprofessionals might then be trained to administer these screening inven-

tories, if interpretation of results and constant monitoring of reliability were the responsibility of more highly trained professionals.

### Stage Three

Based on the findings from Stage Two a child might be referred to a Stage Three assessment of functioning. This stage of the developmental review would include aspects of the four domains listed above: biological, psychological, family and environmental/social/cultural.

In the *biological domain,* one might envision a child being referred for careful neurologic assessment, or for an extensive physical examination and review of health history. The health history, as specified in the guidelines of the American Academy of Pediatrics will also yield a great deal of pertinent information on development.

In the *psychological domain,* the recommendation is that an adequate developmental review cover behavior representative of a wide variety of functions:

### Cognitive Development

Cognitive Skills
Judgment and reasoning processes (as opposed to outcome)
Memory
Interest and skill at gaining information
Information about the world
Integration and organization
Attention, persistence

### Coping Strategies

Characteristic patterns of dealing with tasks
Motivation

**Social Development**

Relation to adults
Relation to children
Self-help and adaptive skills
Concepts of responsibility and moral dictates

**Emotional Development**

Affect expression and control
Self-concept, self esteem
Body image
Individuation
Concept of competence

**Language and Speech Development**

Receptive language; language comprehension
Expressive language
Articulation
Fluency

**Auditory Perception**

Discrimination
Auditory memory

**Visual Perception**

Visual
Visual motor
Visual memory
Visual integration
Visual sequenceing and reasoning

Movement, mobility
Gross motor
Fine motor

In the *family domain,* one might use any number of currently available family stress inventory outlines. One would, in addition, be investigating the issue of what familial factors are available to support the healthy development of the child. One would like to know about parenting issues such as: do the parents feel they understand the child, do they accept the child as he is, do the parents feel in control of the child or is he "beyond" their control, and do they essentially trust the child. A variety of economic, historic, and human relationship issues might be reviewed for their strength-giving aspects in child development.

It must be emphasized that the identification of emotional and behavioral difficulties, and problems with social development or parent/child interaction, should be left to parental or child initiative and sensitive clinical observation. Clinical inquiry as it is normally carried out with parents and children by a skilled professional must be employed at this stage. *The use of a systematized standardized procedure inquiring into these issues is ethically unacceptable.*

In the *environmental/social/cultural* area, one is essentially again looking for the factors to support the healthy development of a child and family. Particularly pertinent here would be the support of community institutions such as schools, hospitals, churches, recreational facilities, and the entire child-care/day care system.

It should be emphasized that at every point in the developmental review, the orientation is toward the child's competencies and forces which are facilitating or could facilitate the child's development.

## Is Intervention Necessary?

The final question, of course, is "is intervention necessary?" The entire developmental review is a process of at-

tempting to understand in successively finer terms the situation of the child and family that would lead to positive action. Numerical results of test items are only one very small part of the picture. The process by which a child arrives at a result is crucial.

One must observe with all clinical skill issues such as working method, attitude, motility, interest span, curiosity, how a child understands his environment, those around him and his own relationships to them. The ethical dilemma of reviewing a child's development, without reviewing the parent/child totality when this is intrusive, but crucial to adequate investigation, must always be raised. It is in this area that some of the basic disagreements of the group were raised. What is clear is that this clinical assessment must be allocated to people highly skilled both in child development and in working with parents, having a very high sensitivity to what to appropriate and what is inappropriate with any specific person. It is for this reason that any extensive review of a child's development must be done by someone with great clinical sensitivity. A true comprehension of what the clinical process is must be conveyed to all people involved in developmental review so that a very clear understanding of the difference between Stage One and Stage Two material as contrasted with Stage Three, the usual diagnostic state, is available. "Screening" is not just faster and simpler; it involves an entirely different process of understanding.

As will be noted, no specific list of tests, instrument or observation schema have been included. It was the feeling of the group that no such list should be made available since it would automatically signify to people seeing the report that these instruments were "acceptable". Two points need to be made: first, that one of the basic areas of disagreement covered the use of instruments acknowledged to be inadequate, simply to have an instrument, and second, that *it is clearly necessary that we do develop instruments in order that the developmental review may be carried out most adequately.* The recurrent theme in reports and discussions is that while it is earnestly desired that there be a uniformly acceptable set of review procedures, relative to psychometric validity, norms, cultural/ethnic validity, etc., there simply is no such set of procedures currently available. It is the hope that such a set of procedures might be developed, and it is strongly urged that the Medical Services Administration take a

leadership role in establishing task forces and demonstration projects to do just that.

It has been noted earlier that while there is not, at the present time, one single fully acceptable tool for developmental review of the psychological domains of cognition, emotion, perceptual-motor functions, or language, there are procedures that have reasonable utility to selected aspects of the developmental review process and are acceptable in certain situations. Any tool must meet acceptable criteria for use. The following criteria are proposed for instruments to be used in the different stages of the developmental review process, whether the review is direct, with the child, or indirect, through the parent or caregiver:

1. Acceptability of the instrument, and its content, to parent, child and professionals;
2. Standardization norms appropriate to the population to be reviewed; to include at least the following: age, sex, race, socio-economic status, and geographic area;
3. Demonstrated instrument reliability;
4. Demonstrated instrument validity, through standard correlation techniques;
5. Demonstrated concurrent validity;
6. Amenability of the instrument to administration and scoring by trained paraprofessionals, if it is to be used in Stage One or Two;
7. Cost effectiveness;
8. Instrument must be published, and widely available.

Given that the instruments to be used are in conformity with these criteria, and with appropriate consideration for cultural, ethnic, racial, and socio-economic factors that may influence interpretation of the findings from the developmental review process, this proposed system of developmental review has the following desirable characteristics:

1. It does not attach a label, or categorize, a child prior to a much more extended review, referred to as a Stage Three developmental review;
2. It makes a dedicated effort to engage the primary

caregiver, the parent, as a collaborator in the developmental review process, and attempts to insure that the interpretation of the findings of the developmental review are culturally relevant, as well as psychologically sound;

3. It establishes definitive criteria for any developmental review instrument to be used, recognizing that the present state of the art does not admit of a single universally acceptable instrument that is applicable to all of the culturally diverse and pluralistic populations involved in the EPSDT program, some twelve million American children;

4. It attempts to establish a brief, workable system of developmental review, that is functionally effective, both in terms of cost and benefits, with, hopefully, a reasonable guarantee of acceptability to both parents and professionals; and

5. It recognizes that there is not, at the present time, a single, universally acceptable tool for developmental review, while at the same time pointing out that there are a multiplicity of such instruments that have practical utility in differing situations, oriented toward review of individual and specific developmental functions.

It should be constantly emphasized that everyone is strongly opposed to any effort to attach "labels", or to make a diagnosis of the child during the first two stages of developmental review. The purposes of the initial review are to engage the parents in a collaborative effort to assess the process of the child, and to identify areas in which process has been perhaps problematic or, alternatively, to identify areas of special gifts that might be enhanced through facilitative efforts. The first two stages of review would not attempt to categorize or "label" children; rather, the system of developmental review would be devoted primarily to determining whether, in fact, there is cause for concern and if so, what further efforts must be made to determine whether the concern is valid or merely reflects transient and not continuing problems. Given this orientation, the question of false positives/false negatives is moot.

The relevant question might be posed as follows: "Is there sufficient consensus between the developmental reviewer, the

parent, and the child (in the case of older children) that there is need for further review?" If the answer is affirmative, then the recommendation would be that of referral for Stage Three review. It is to be noted that the assumption is that Stage One review (other than the health examination in some locations) will be done by paraprofessionals, while Stage Two would be most likely a combination of professional/paraprofessional efforts, i.e. the administration but not the interpretation of the developmental review instruments will be conducted by paraprofessional personnel at this stage. Stage Three must be carried out by experienced and skilled professional clinicians. On a concrete level, it is recommended that whenever the performance of a given child at Stage Two deviates by more than 20% either above or below what would be expected for chronological age norms for that particular developmental review instrument then the findings from the developmental review for that child should be assessed to determine whether a Stage Three referral should be made, or in the case of a child who has special gifts, to make special efforts to assist parents in seeking out means to facilitate the special talents. It is to be stressed that this proposed method of identification of children who may be at risk for developmental difficulties is both empirical and objective, and does not "label" or diagnose a child. Rather, it simply indicates that optimum developmental progress is either not occuring or is occuring at an accelerated rate. Thus, the system of developmental review as proposed recognizes that there may be strengths as well as weaknesses, and moderates the search for pathology that is the hallmark of other systems of developmental assessment.

It should be pointed out that the areas of basic disagreement were four:

1. Any review of the adequacy of parenting skills was an anxiety provoking area for many. This is discussed in fuller detail in the section on legal and ethical considerations.

2. Using instruments that are acknowledged to be inadequate, simply to have an instrument, was a further area of disagreement.

3. The absolute need not to make up lists of "approved" tests was felt strongly by many. It is suggested, however, that it would be possible to supply a list of tests

currently available with information on how they meet the criteria of appropriateness reviewed above. A separate task force could do this in a brief time, making the point always that the situation is much more complicated than many people believe.

4. In terms of the content of screening instruments, the question of whether we are ready to move from small scale to country-wide on any available instruments was an issue. The vast social implications of what we do were constantly before us.

## 4. The Role of the Parent

Clearly underlying the approach to developmental review suggested herein is the premise that a child's cognitive and emotional functions do not develop in vacuo. Although this appears to be a truism, it is unfortunately also true that this "truism" rarely informs the development of programs.

Health care is often delivered without the involvement of the parent. Our belief in the importance of the "engagement" of the parent in the system, in the use of information from the parent in the developmental review, and in the involvement of the parent in the full-scale treatment programs should be stressed.

> Relationships between parent characteristics and child health and child development and the greater long-term effectiveness of parent centered as contrasted to child-centered early education programs suggests that child health programs should have a major goal of supporting family care of the child. A comparison of major characteristics of parental as contrasted to professional interaction with the child—priority, duration, continuity, amount, extensity, intensity, pervasiveness, consistency, responsibility, and interfamily variability—suggests the need for a major focus on the role of the parent in the EPSDT program. Traditionally parents have had primary responsibility for the integration of screening, diagnosis, and treatment services for their children. Parental cooperation with health workers is essential in order to make EPSDT services available to their children. There-

fore, a major component in planning State and local EPSDT programs will be to develop communication and collaboration with parents and with parent groups.

To achieve the needed collaboration between health and welfare professionals and parents will require training of both parents and professionals. Health and welfare professionals should understand the role of the family in child health and should have skills in strengthening and supporting as well as supplementing family care of the child. Workshops and inservice training programs for health and welfare workers on the conceptualization of family care, on variables that influence family care, on the relationships of parental care to child health and child development, and on new methods by which professionals and paraprofessionals can strengthen and support parental care of the child are needed. The programs should motivate increased collaboration with parents in providing for the needs of children. Programs that train and motivate parents to become involved with review of developmental progress and with diagnosis and treatment through outreach programs, followup programs and continuing home visitors programs are essential to insure early and continuing care of the child. (Schaefer, 1974)

In developing a parent questionnaire, it is obvious that the questionnaire must not be trivial, must have developmental implications, but most importantly, must have cross-cultural validity. There are in the United States a number of such parent questionnaires currently being used.

A second area of important contribution of parents to developmental review is the review of the family environment. The purpose of this is to describe the characteristics of the family and the social and economic circumstances in which it finds itself, in order to identify the stresses and the strengths and support systems available to the child. Some questions which might be added to the physical examination have been discussed in Stage One screening. In addition to this there is the possibility that, with parental approval, a local group might choose to add considerations of a more extensive sort in understanding the family support system. Under these circumstances, an approach such as that suggested by Mercer in discussing measures of sociocultural modality might be accepted:

1. family structure
2. Anglization
3. occupation of head-of-household
4. family size
5. parent/child relationship
6. sense of efficacy
7. source of income
8. urbanization
9. community participation.

Some local areas may choose to focus on a "problem list" such as economic stress, marital discord, parent depression, and the like. There are several family stress questionnaires currently available.

It is clearly essential that parents understand their children's abilities and assets as well as their disabilities and deficiencies. What a child can do is far more important than what a child cannot do. The dialogue which brings parents and children into a true health care system is vital. We must also think seriously about developing parent-based treatment models right at the beginning of the programs. This crucial aspect of health care is frequently ignored. Treatment in this area of development frequently involves educational programs for parents on how to work with their children, and educational materials about life styles and health impact on family organization. "Treatment" may be education of the parent to support the child's strengths.

A recently published review of intervention strategies for high risk infants and young children (Tjossem, 1976) reviews an entire series of parent projects. In assessing the availability of treatment resources in local communities, most frequently the most obvious resource is omitted—the parents. It is possible to help parents learn to work with their own children in a way that has been highly productive not only for the children but also for the parents themselves. It is recommended that a separate task force be developed that would collate and then make available to local communities the varying models of parent based "treatment" programs that have been developed, and also make available to these local communities the wealth

of parent education material that currently exists in many scattered places. This particular use of parent education materials holds within it a truly exciting and innovative approach to health care in this country.

## 5. The Delivery System

*Our first recommendation is that the EPSDT mandate be broadened to apply to all children in this country so that a system of developmental review and of developmental protection might be planned for comprehensive implementation.*

This will undoubtedly require the establishment of guidelines for eligibility of families who will qualify to receive these services paid for by Federal funds and for sliding fee scales for other families, but we believe that the service delivery systems contributing to the goals of EPSDT ought to serve the needs of all children in our society. Primary prevention and early intervention programs should be available to all children and youth. The identification of EPSDT as being available only to poor children is detrimental to the poor and nonpoor alike, as well as to the long-term viability of the program. It also detracts from the potential of our efforts to conserve our most valuable resources for the future—our children.

*There is extensive overlap in functions and goals of several existing Federal programs. In the interest of pooling resources, consolidating efforts, and effecting maximum impact, we recommend that such overlap be eliminated, possibly through mandated merger.*

It is premature to say whether actually merging programs is possible or desirable, or whether EPSDT should have the key coordinating role, described below. We need to know a great deal more about how each of these programs operates, how they are administered, what services they can provide, to whom, and in what kind of setting, which are most acceptable to families and can best reach them, etc., before any decision can be made regarding the most reasonable and effective relationship of each to the other. Nonetheless, intensive efforts at coordination, collaboration and linkages must be continued and strengthened immediately.

Specifically, the Maternal and Child Health program and the Education for All Handicapped Children Act (PL 94–142) are programs having significant duplication of effort with EPSDT. A thorough review of existing programs and agencies serving children should be undertaken, with a goal of effecting such mergers as would improve our services to children and reduce duplication. Added to such a review should be programs sponsored by NIMH, NICCHD, BEH and OCD/Children's Bureau. Care must be taken, however, that existing services provided by current Federal programs must not be lost if and when a consolidation of effort should occur. For example, it would be unfortunate if the services now funded by Crippled Children's Services were lost in the "merger".

**Interface of Medical and Educational Settings for Achieving the Goals of EPSDT** (hereafter EPSDT refers to a merged program)

In order to facilitate the interface of medical and educational settings and, as well, social service delivery systems for the purpose of achieving the goals of EPSDT, we are recommending the establishment of an EPSDT Coordinating Office at the local level to be staffed by an EPSDT local Coordinator and supporting personnel. It will be the function of the Coordinator to insure that the screening, diagnosis, referral, treatment, information dissemination, and follow-up resources of the community be brought to bear upon carrying out the goals of EPSDT. It will be the function of the Coordinator to relate to the medical, educational, and service agency settings so that each contributes its competence in providing developmental review and protection for all children in the community and for individual children who need special services.

Developmental review and protection of the child begins during the prenatal period. Pregnant teenagers and pregnant non-teenagers need to be provided with a health delivery system that offers both medical and educational services. Through information dissemination and by relating to the schools, physicians, clinics, county health offices, welfare agencies, and individual families, the EPSDT local coordinator should work to insure that every pregnant woman is entered into the health delivery system as soon after the onset of pregnancy as possible.

Initial developmental review becomes possible in the first few days of life in the hospital setting on the basis of present-

ing conditions, some infants will be classified as high risk for normal development, some will be classified as suspected risk, and some as normal. Later developmental delay and disorder may be expected from all of these groups, in differing percentages. The normal pediatric exam needs to be supplemented by an additional screening instrument. None presently exists that can be conveniently implemented. However, we are recommending that, subject to parental consent, each newborn infant in a community or designated EPSDT district be entered in a birth registry and slated for periodic home visits by an EPSDT home visitor. The home visitor would be expected to make contact wth the parents prior to the infant's dismissal from the hospital, to conduct or arrange for subsequent metabolic and/or blood screens that can be done in the home at 10-14 days and to offer the parents pertinent information concerning early child development and resources available in the community including clarification of the full range of services available from the EPSDT Program. If developmental problems are observed by the home visitor (as the result of general observations, parental concerns, or the application of a Stage Two developmental screening test) referral to appropriate medical or developmental services for Stage Three evaluation would be made if the parents are agreeable. With parental consent the home visitor would facilitate communication with the child's physician if the child is being served by a physician or would refer the child and his/her family to appropriate services. Home visitor's work should be under the supervision of the EPSDT Coordinator and be assigned in accordance with neighborhood or community EPSDT districts. However, flexibility in program requirements should be maintained; if lodging the home visitors with an existing community service rather than in the office of the Coordinator makes more sense for a particular community or neighborhood, such arrangements should be permitted.

The frequency of visits would be determined by a needs assessment by the home visitor. Visits to the home will continue until the child has been engaged in a system that provides health care overtime. The home visitor's role would serve educational goals, permitting developmental review to take place and would facilitate referral and follow-up. At any time, upon parental request, the home visits would be discontinued.

Public health nurses, pediatric nurse assistants, developmental psychologists, and other professionals with special training might serve as home visitors for the purpose of providing special services to the family (e.g., home based developmental programs for young infants).

At the end of the preschool period and just prior to entrance into the public school, the question of the interface with the public schools for purposes of information transfer will need to be faced. Children identified by the EPSDT program as having been recipients of services may or may not be served by having information communicated to the public schools. It will be the responsibility of the EPSDT Coordinator to arrange for service agency personnel providing services to the child to meet with the parents of the child for the purpose of making a decision concerning information transfer. Such developmental information transfer is recommended only when the information would be helpful in identifying the conditions under which a child functions best, so as to enable optimal school placement. It is our recommendation that only diagnostic information that is pertinent to educational prescription for the child be communicated to the schools, subject, always, to informed parental consent. We are assuming that normal medical information typically required by school systems at the time of public school entrance for all children would continue. As the child moves across systems or within systems, information transfer should only occur when the parent and service provider agree that it is the best interests of the child. With due consideration of age and maturity the child's consent should be included as a condition for information transfer.

During the years in which the child is enrolled in the public school, the teacher and parent are always the first line of information for developmental review. Special training programs will be recommended which will enhance the developmental surveillance and protection role of the teacher. It is in relation to the entrance into public school that the recommendation for the close collaboration or merger of PL 94-192 and EPSDT is most relevant. This "merger" of the mandates of PL 94-142, Maternal and Child Health and EPSDT will maximize the resources available for developmental protection of children during the school years. We recommend leaving to each State the implementation of goals of these "merged" mandates via interagency agreements and local coordination of services and

agencies. Identification of individual educational needs should be part of an ongoing program, to be followed up by the provision of relevant services. During the adolescent years, educational or direct experiences which contribute to develop mental readiness for parenthood and adulthood should be made available.

In an attempt to insure that services are made available, states should be required to outline a phasing plan for EPSDT implementation beginning with outreach and covering start up and activation of the full range of EPSDT services and providing for multiple entry points. Local EPSDT Coordinating Councils should be established with representation from the schools, health services and other appropriate agencies; parental representatives must also be included.

## Recommendations Concerning Support Systems for EPSDT

Two major support systems were mentioned in the preceding section. Recommended is the creation of an EPSDT Coordinator, and EPSDT office and support personnel for EPSDT districts. Where feasible, these districts should be formed to be coincident with local school districts, or to be larger or smaller than existing school districts depending upon population density. Also recommended is the establishment of EPSDT Community Coordinating Councils (as noted above) to include the schools and all service agencies as well as including representatives of parents and service providers.

These support systems are being recommended in order to enable and facilitate 1) planning on the local level; 2) identification of gaps and needs in the service resources; 3) coordiation and stimulation of services relevant to achieving goals of EPSDT; and 4) cooperation and contribution to the external evaluation of EPSDT.

As is obvious from the foregoing recommendations, there is an absolute necessity to examine any local situation prior to initiating a program. Questions involved in a health needs assessment of a community would give answers to "who is there to do it", "what are the supportive institutions", and "what facilities are available to work with parents in developing the fullest treatment programs."

The manpower issues involved in training, consultation, and technical assistance are primary. To be carefully reviewed, again in each local situation, are issues of qualifications of personnel involved in each stage of developmental review, cultural appropriateness of these personnel, and their training and education. Each natural system on a local level would include not only the professional system but the highly valuable, and indeed critical, sources of information and support, the parents. The characteristics of each natural system need to be defined for each locality. *We clearly are recommending multiple models of service delivery depending on the characteristics of individuals and agencies available as support systems.* The local coordinating councils may decide on resource centers with transportation to these centers, on the use of mobile units, on the use of community college personnel, on a multitude of other mechanisms for obtaining services. Again, improvement in the health status of children requires meeting a large volume of unmet needs for health care as well as for changes in environmental, social and other factors that clearly affect health status but are outside the scope of a reimbursement and support system related only to health services delivery. For this reason our emphasis on coordination of program and payment mechanism must be taken seriously.

Existing programs which hold enormous potential are not adequately meeting the needs of America's children and families. Federal programs are scattered among dozens of departments and agencies.

> This fragmentation creates problems of coordination at best and conflict among programs at worst. At the state and local level the situation is even more confused. A wide range of services to families and children is currently being provided in an essentally haphazard fashion from many different government agencies and private organizations. Despite the sporadic attempts at community and regional planning and coordination, the result has been inadequate coverage in many localities and duplication of effort in others.
>
> Categorical, single strategy programs, while effective in meeting some of the specific needs of many families have failed to provide the support required by many families with multiple needs. In addition to programs specifically

directed toward families and children, public policies in many areas have effects, both positive and negative, on the welfare of families. Despite this fact, little explicit attention is given to the impact on families and children of welfare, health, housing, transportation, environmental regulation, criminal justice, recreation, consumer protection, and other programs, both old and new. (Toward a National Policy for Children and Families, 1976)

**The Parent and Support Systems**

To be emphasized repeatedly in this approach toward coordination of services at a Federal and local level is the role of the parent.

> Support not intervention for parents of young risk children has emerged as the most promising available approach for producing developmental gains. Findings show that parents are effective teachers of risk children if given appropriate support. Their success in enhancing their child's development rests largely upon their motivation, involvement and acceptance of responsibility. The early relationship established between mother and infant is given as a fundamental determinant of the child's later course. With acceptance of these principles and the family as the object for support, communities can organize supportive services that enable families to enhance their risked child's development.
>
> Ideally, the approach begins in the newborn nursery. Here, both physicians and nurses are alert to sounds of early risk and show concern for the child's developmental well-being as well as health. In their appraisal, signs of risk in the early mother-infant relationship are not ignored. With evidence of risk and need for support, mother and child are discharged with an accompanying referral to be community health services for nurse support and observations in the home.
>
> In her home visit, the nurse first gives expression of the community's interest and support for the future well-being of the risk infant and family. While observant of total family needs as well as the health of both mother and child, the nurse is supportive of the mother's ben-

eficial child care behaviors. She continues her periodic visits until, after exchanges with the child's physician, determination is made that no risk or continued risk is present. With this determination, she maintains her visits and relationship with the risk child and family and terminates services to the child and family that are doing well.

In the continuing supportive relationship, the nurse extends her knowledge of child care and training to the child through the mother. For family and child requirements beyond her command, she draws upon her knowledge of community or area resources to bring them into family service. In this manner, referral of the family is made to the community's educational resource upon evidence of the risk child's needs for educational assistance in mastering the developmental tasks of childhood.

The transition from nurse and physician to education services brings with it a comprehensive understanding of the child's health and developmental status and the family's needs and strengths. Upon educational evaluation and acceptance for service, the child and family enter into the home-based training program offered by the educational resource. The individualized training program is implemented by the parents with the guidance and support of the educator. Continuing, as needed, into the preschool years, the educator monitors the family's and child's needs for adjunctive community services and assists in bringing their support to the family.

The parent approach outlined in the foregoing is but one of the many models a community might develop to provide services to risk children. To the extent that other models capture the basic principles involved, they should be effective programs. These principles restated are:

1. supportive services are initiated early
2. are offered on the basis of perceived risk and need, not diagnosis
3. are family oriented
4. support and enhance the mother-child interaction system, and
5. are sustained.

> The requirements of the basic program are modest and can be met. They exist as medical, nursing, and early educational services provided in most communities, or, in their absence, can be developed through existing agency organizations. The resources and technology are, or can be, available. The task, now, is to make them work. (Tjossem, 1976, pp. 24-25)

## 6. Payments and Eligibility

The coordination of services and programs discussed in the preceding section obviously dictates coordination of payment and eligibility issues. It is a strong recommendation of this group that the "merged" EPSDT Program be available to all children and families in the United States. It is also urged that funds be made available for development of health care resources, including considerations of manpower, facilities, and research and development.

In the current situation, EPSDT turnover in eligibility negates the periodic aspect of EPSDT and may deny treatment found necessary as a result of developmental review. There are lapses in eligibility and these lapses are a clearly demonstrated problem. Patients may not be eligible for services long enough to receive treatment for identified developmental problems, or their treatment may be interrupted on the basis of eligibility issues. Currently, eligibility for EPSDT depends in most states on eligibility for welfare services, and health care needs do not necessarily correspond to welfare status. EPSDT reconfirms the limitation of "means-tested medicine", and the need for a more continuous and comprehensive method of assuring the right to treatment for people whose incomes often vary widely from month to month.

## 7. Ethical and Legal Considerations

### General Ethical/Legal Premises

In developmental review, ethical evaluations must be viewed against the backdrop of two different normative models: 1)

the disease recognition and prevention model and 2) the cultural diversity model. The former emphasizes identifiable organic pathologies which imply some type of medical treatment. Within this model, the basic assumption is that false positives carry no risk aside from those associated with further diagostic procedures, while failing to detect pathology could lead to serious and possible irreversible consequences.

On the other hand, the "cultural diversity" normative model focuses on behaviors which deviate from the expectations of the social group. In this case, the basic assumption is that false positives are more serious than false negatives in screening because labeling a child as deviant tends to trigger social responses such as labeling, tracking into special programs, institutionalization, changed perceptions and expectations, etc., which in themselves may have irreversible consequences. For this reason, emerging law in the area of mental retardation and juvenile justice clearly rests on this assumption.

Thus, any developmental review system initiated under EPSDT should clearly reflect this important distinction. In our view, screening may legitimately utilize the "disease model" during the years of infancy and early childhood development when the child's primary social group is the family. In doing so, however, developmental review must focus primarily on the child's "physiological" development. Conversely, as children enter the mandated school system, when their behavior is evaluated with reference to the expectations of the social group, developmental assessment necessarily encompasses behavioral measures, and policies must therefore be formulated within the normative framework of the "cultural diversity" model.

## The Scope of Developmental Review

In a free, pluralistic society, there are clear boundaries on the scope of legitimate inquiry into personal and familial concerns. Therefore a mass, government financed screening program should be limited to 1) those measures of organic functioning and basic, adaptive coping skills which enjoy a high degree of consensus within the health professions and affected communities, and 2) those behavioral factors espe-

cially associated with learning, language and speech development, motor skills and perceptual abilities. Specific assessment of emotonal and behavioral adjustment and parent/child interactions should be let to parental initiative and sensitive clinical observations (Stage Three as herein proposed).

**Relationship Between Developmental Review and the Remainder of the Health Care Delivery System**

1. Programs should not be instituted without careful attention to their place in the full service delivery system: coordination of services as recommended in Section E is vital.
2. A top priority is the identification of gaps in diagnostic and treatment services in each community as an integral part of health services needs assessment.
3. There must be some mechanism for assuring the quality and equivalency of all developmental review and treatment services in the community.

**Relationship Between Developmental Review and Unavailability of Follow-up Services**

It is not ethically mandatory to limit the scope of review by precluding a specific review procedure because treatment is unavailable for the identified condition. This is true whether or not there be known treatment at all, or treatment is not available in the community, or if available, is too costly. Reasons offered for this position include:

1. without such data, the need for the development of treatment capabilities may never become apparent;
2. the information may be useful to the provider in counseling the parent about managing the problem, and in developing parent oriented treatment programs;
3. treatment may later become available.

However, in many individual cases, it is likely that the cost of Stage Three review would be unjustified by its likely benefits to the child.

### Informing Parents of Results of Screening

If the developmental review program suggests that the child is in developmental difficulty, the health professional should inform the parent of the general area of concern, being careful to avoid arousing undue parental anxiety, before recommending referral for diagnostic (Stage Three) evaluation. If the diagnosis is positive, the clinician should inform the parents fully of the child's developmental status and discuss the treatment alternatives. If treatment (or perhaps even diagnostic) services are not available in the community, then the diagnosing clinician should counsel the parent, utilizing his/her own clinical judgment in determining what information to disclose. It is, of course, also important to inform parents when no indications of difficulty are found during any of the stages of developmental review.

### Criteria Governing Use of Standardized Procedures

1. We accept the view that American society is heterogeneous. Therefore, standardization of all procedures used in screening or diagnosis which are correlated with sociocultural factors must be done with appropriate sociocultural norms, and all testing must be administered in language appropriate to the language spoken by the child. Further criteria for appropriateness of instruments are spelled out in Section 3.

   After two years, no standardized procedure should be utilized in the program until it has been approved pursuant to regulations adopted by the Secretary. In the interim period, a task force appointed by the Medical Services Administration shall review standardized procedures currently in use, with the advice of appropriate professional and consumer groups, to determine whether they are correlated with sociocultural factors.

2. Each standardized procedure should have predictive validity for the behavior or conditions which they purport to measure. They must have predictive validity for children of each of the sociocultural groups with whom the procedure is to be used. After two years, no standardized procedure should be utilized in the program until it has been approved pursuant to regulations adopted by the Secretary. In the interim, the task force appointed by the Medical Services Administration shall review the predictive validity of standardized procedures currently in use for compliance with this standard.

**The Ethical Relevance of Cost**

Cost becomes an ethical issue when government, with limited resources, must finance services for large numbers of children and must choose to what extent which children can and will be served.

Although reliable cost estimates are presently not available for screening, diagnosis and treatment for EPSDT children, it is clear that such procedures should be as low cost as possible with the highest return.

Considering these premises, we suggest the following guidelines for priorities for the EPSDT Program:

1. Priority for care should be targeted to the prenatal, infancy and clearly childhood periods until the child reaches the mandated school entry age.
2. Stage One and Stage Two review procedures should be as quick, brief and simple as possible without sacrificing quality so that as high a proportion of funds as possible can be put toward treatment.

**Informed Consent**

1. Parents
   a. As an integral part of the initial outreach phase of a developmental review effort, parents should be

provided with a written description of the nature and purpose of the proposed procedures, including adequate assurances of quality, confidentiality and benefits to the child and family. Any written notification should include information in a language appropriate for that particular family.

b. At the time the parent personally appears, he or she should be verbally informed of the nature and purpose of all developmental review procedures, and should be notified that selective participation is possible. A refusal to authorize any given procedure must not jeopardize the child's access to any other aspects of the program. Parental consent should then be obtained for each procedure and for any proposed transfer of records or information upon completion of the developmental review.

2. Informing the Child

Each child being served should be informed of the nature and purposes of the procedures and their results to the maximum extent possible consistent with his or her level of intellectual and emotional maturity.

**Records and Confidentiality**

All patient records should be created and maintained in accordance with the customary practices of the health professions. Confidentiality should be carefully preserved and no information should be released without parental consent.

At the time of the mandated school entry screening, all records of earlier developmental review at time of birth, during infancy, or at time of pre-school entry would be consolidated by the EPSDT Coordinator. It will be the responsibility of this Coordinator to arrange for service agency personnel providing services to the child to meet with the parents of the child for the purpose of making a decision concerning information transfer. Such developmental information transfer is recommended *only* when the information would be helpful in

identifying the conditions under which a child functions best so as to enable optimal school placement. It is our recommendation that only diagnostic information that is pertinent to educational prescription for the child be communicated to the schools, subject always to informed parental consent.

1. Under no circumstances should Stage One and Stage Two information be transferred to the school system.
2. "Medical" information from these records may be disclosed to authorized persons in the educational system with parental consent in accord with usual procedures.
3. "Screening information" per se should not be disclosed at all.
4. Additional information from the records may be disclosed to authorized persons with parental consent only after the EPSDT Coordinator has consulted with the parent and they have made an independent determination that the disclosure is in the child's best interest. With due consideration of age and maturity, the child's consent should be included as a condition of information transfer.

**Ethical Aspects of Developmental Review and Assessment After Mandated School Entry**

Many of these ethical and legal concerns about the purpose and scope of developmental assessment, informed consent, parental and child roles and confidentiality of records are especially acute after the child has entered the school system. This committee recognizes the school as a major point of impact on the child's development at this stage of his life. We also recognize our mutual concern with the critical aspects of a child's development at this point, since much of this development affects school adjustment and learning ability. There are some safeguards built into the education system to address our concerns for safeguarding the child's rights (such as the Buckley amendment) and more will doubtless come with implementation of PL 94-142. Nonetheless, the EPSDT Program should not abdicate nor delegate its respon-

sibility for the children because they have entered the educational system. It requires instead that the criteria outlined interface with the safeguards in the education system, and buttress it when there are gaps. In fact, the "merged" EPSDT with its concern for the over-all health and well-being of the child, should feel that its responsibilities may supersede the requirements of the education system whenever safeguards for the child's rights in these processes are concerned.

## The Dangers of Labeling

> "It would be unconscionably myopic to entirely overlook some of the larger societal issues inherent in any national massive screening system. The legal ethical and ethnic ramifications of labeling humans are to be carefully considered and respected, especially in light of the recommendations forthcoming from the 1971 President's Commission on Mental Retardation in Monte Corona, California which severely criticized current labeling practices and their subsequent dehumanizing efforts. For example, the determination of cutoff points separating normal development from abnormal development is extremely controversial and the Boston conference focused much discussion and debate on this crucial issue (PCMR, 1973.)" (Meier, 1973)

In a working paper prepared for the National Advisory Committee on Classification of Exceptional Children, Mercer addresses this normality issue:

> "The classification of exceptional children has become a critical social problem because those ethnic and cultural groups disadvantaged by present classification systems are protecting the taken-for-granted value frame within which psychologists, educators, and test makers have been operating. The classification of exceptional children did *not* become an issue because psychologists, educators and medical practitioners were dissatisfied with the present system. This fact has great importance to the deliberations of this committee. It signifies that the central issues are conceptual and ethical rather than technical and empirical. It means that basic assumptions are

being challenged. The committee must be willing to examine basic assumptions and to address the fundamental value of questions being raised by those who take issue with present policies and procedures. If, instead, the committee treats its task as merely setting guidelines for establishing the reliability and validity of measurement techniques in their traditional sense, its work will have little relevance to the current controversy because it will have misunderstood the nature of the controversy. The value issues must first be clarified and the implications of adopting a particular value frame explored." (Mercer, 1972b)

We would call attention to the crucial nature of this statement for implementing the provisions of EPSDT, for beyond the ethical issues lie the dangers of legal action. Test results are used for making far-reaching decisions about children. In recent years, a growing controversy regarding the use of tests has blossomed. It has become increasingly apparent that the large scale use of tests for placing persons in social, educational and economic niches has serious social consequences, particularly in light of the growing realization that standardized tests are unfair not only to the culturally different and the socio-economically disadvantaged, but also to the bright unorthodox person and the naive individual who lacks experience in taking them. There are potentially biasing effects of ethnicity, language, socio-economic level, and conditions of test administration on test performance. "Increasng social demands seek to modify existing uses of tests that are inappropriate and unfair, particularly with minority group children. Social pressure in this regard takes various forms, and principally includes litigation, action by professional and other types of organizations, and legislation." (Laosa and Oakland, 1974)

The messages that a child receives about himself from his environment determine to a great extent his feelings about who he is, what he can do, and how he should behave. Thus, if parents or teachers perceive children as different in some way, they will treat the child differently and may thereby encourage him to become as he is perceived. Teachers give the least acceptance and support to children they perceive as having the least promise and the least backing from parents. Teacher contacts with "low assessment" children tend to be significantly more directive and discouraging of initiative and

spontaneity. When adults believe a child to be incompetent, they may protect him from exposure to experiences from which he may learn greater competence. Learning is heavily involved with the expectation that one is able to learn.

### Specific Minority Issues

There is a prevailing attitude, based on economic considerations in many minority groups, that one ignores all conditions which do not cause pain. One of the major issues in any comprehensive system of developmental review is: what form of outreach must be designed and employed which will impact upon the pattern of health facility non-utilization which is so firmly established within poor minority families, and which interferes with the early detection of factors which may potentially lead to poor intellectual and emotional functioning.

### Why Our Fears Will Not Be Stilled

The perhaps repetitious insistence on the appropriateness of instruments and the inappropriatness of labels comes from the experience throughout the country of harm that has been done to children under the guise of "doing good." Children have been tracked and labeled, excluded from school, on the basis of the use of psychological instruments. In addition to this, the issue of parental and teacher expectation is a daily consideration. Children taunt each other, and guilt and anxiety are easily aroused in both children and families. The basic rights of children must be considered in any program of developmental review. The *motto must always be "first do no harm".* In the EPSDT system, there is the potential for enormous good.

## 8. Evaluation

Program evaluation is a highly specialized field; it is recommended that specific guidelines concerning program evalua-

tion be developed by a task force of experts who have specific competency in this area. We caution that this must be done quite soon, so that elements considered essential to proper program evaluation be included in those programs now in the process of implementation.

Evaluation of EPSDT should be done in relation to specific, predetermined process and outcome measurements. An effort should be made, however, to insure that the evaluation of the developmental review segments of EPSDT does not itself become the controlling factor in the operation of the EPSDT program where such control would deflect the program from achieving its goals. Any evaluation program to be implemented must be done so with a minimum of paperwork and with the least distortion or interference in the operation of the program.

Process evaluation would be relatively easy to implement since it involves such matters as utilization, cost issues, volume of service and so forth. Outcome evaluation is much more difficult and more demanding, but must be done since the issue of long-term predictability of any aspect of developmental review is one that is crucial for the future of the children.

## 9. Cost Effectiveness *

Any publicly financed health program begins with the assumption that it provides benefits which are an adequate return on the investment of public funds. Otherwise, the government need not institute a program at all. It could let the market place regulate health care without interference. During the past forty years in the United States the government has gradually increased its share of payment for personal health services. In child health, the government paid out 3.5 billion dollars in 1973 for welfare recipients and the medically needy, which has thereby become the major governmental child health program in both numbers of recipients and dollars expended.

The history of the federally and state financed Early and Periodic Screening, Diagnosis and Treatment Program indi-

* This section has been adapted directly from the working paper written for the conference by Anne-Marie Foltz, "The policy dilemma: screening and cost effectiveness".

cates that it was established on the overall assumption that early detection and treatment of disease will save lives, save suffering and save the costs of life-long crippling conditions. Further, it was assumed that screening and early detection of disease can alter the natural history and course of a disease and that the benefits of this alteration can be quantified in dollar amounts. These cost-benefits assumptions were never fully documented so it is difficult to know precisely what were Congress's expectations when it passed the law in 1967 (P.L. 90–248). Thus, an evaluation of the program based on congressional goals is not possible simply because these goals were never clear.

In actual fact, despite the grandiose title of the program, it was planned and implemented in such a way that prevention and screening have been the focus, while diagnosis and treatment have been secondary if not neglected. Continuity of care has remained a distantly hoped for goal.

It was hoped that the burden of handicapping conditions would be removed by providing preventive care services for children. The Department of Health, Education and Welfare thereby thrust itself in the midst of a major debate in the field of medicine and public health which has been described as medicine's great schism: prevention versus cure.

Not only has there been no discussion of exactly what was to be prevented through the new program, there was no commentary on how effective a preventive program might be. Given this imprecision of purpose, it is no wonder that costs of these programs were even less clearly stated.

One way of controlling costs in implementation is to limit the extent of services that states are required to provide. In monitoring the programs in the states, HEW decided to focus its attentions on EPSDT and not to look at the overall care rendered under Medicaid to welfare and medically needy children.

The efficacy of disease management through screening rests on three necessary conditions: a knowledge of the natural history of the disease; the efficacy or efficiency of the treatment; and agreement on a large number of social and individual benefits which may accrue from the screening procedures. For screening to be efficacious, there must be a consensus on the social and individual benefits of the treat-

ment procedures, and it is here that the developmental screening aspects are most vulnerable.

Few cost estimates have been made of the developmental screening components of the EPSDT program, particularly in relation to benefits. In the past, the issue of quality of care as measured by appropriate utilization has been constantly confused with the issue of costs. Sometimes costs are evaluated; sometimes costs are noted only in terms of the substitution of expensive services for less expensive services into contrasting organizations of health care. Costing out the EPSDT program and assessing cost effectiveness has received far less attention than studies for the Medicaid population as a whole. As in the case of developmental screening, the state of the art of cost effectiveness is not far advanced. Almost no work has been done on cost effectiveness for any system of developmental review; cost effectiveness itself may not be highly relevant if the goal is to provide children with relevant and promotive access to health care. A "merged" EPSDT, seen as a comprehensive care program, provides a basic package of health services which should be available to any child in the United States regardless of his economic status.

One does not need cost benefit analyses to prove that poor children should have access to the same health benefits as rich ones. Nor does or should one need cost benefit analyses to decide that children with crippling conditions deserve care. The analyses become useful, however, when, given limited resources, policy makers must decide how much of what sort of care can be given to how many people.

EPSDT's significant contribution to the field of child health has been to uncover the present health system's inability to provide comprehensive and continuous health services for poor children, even given a financing mechanism. The reasons for this failure are diverse:

1. The state of the art of preventive health services, particularly with reference to developmental review: disagreement among health professionals as to what is required and what is needed.

2. The inability of organized systems (state health or welfare departments) to monitor and follow all children under their care: the lack of case management systems.

3. The unwillingness of private health professionals to participate in a public health system unless adequate financial incentives are provided and bureaucratic dis-incentives are removed.

4. Confusion among federal and state agencies as to which group is responsible for child health (for example, Maternal and Child Health, Medical Services Administration, the Office of Child Development, etc.).

Research must be continued to provide answers to cost issues, and to develop appropriate systems for collection of data to estimate costs and benefits of publicly financed child health programs. The goal is, obviously, to determine the most economically feasible methods to deliver services without sacrificing quality.

The field of policy is extraordinarily important. If Congress meant what was stated in the EPSDT legislation, to make comprehensive care available for every poor child, then it must follow through on its promises and abandon cost effective approaches which subvert the intent of the policy.

## 10. Training, Research and Demonstration Projects

The proper implementation of EPSDT across the country will require the development of training programs in order to increase the sophistication of professionals in the area of normal development, developmental review, and opportunities for the developmental protection of children. Therefore, we recommend that there be an expansion of existing sources of funding so that training programs necessary for existing professionals who will contribute to the achievement of the goals of EPSDT may be made available. We include in the group of eligible professionals: physicians, nurses, teachers, psychologists, social workers, school counselors, and speech pathologists and audiologists. Training programs should be carried out by existing accredited training resources and institutions (for example, universities, state colleges, community colleges). Training could be offered in the form of workshops, courses, seminars, and inservice training programs. We also recommend that training funds for paraprofessional personnel be made available on the assumption that Stage One and per-

haps Stage Two of the developmental review process will be carried out by such personnel, and on the assumption that a great deal of the parent support work will also be carried out ultimately by paraprofessionals.

We urge increased effort to sensitize physicians and other health professionals to the problems of parents and to the problems of ethnic diversity within this pluralistic society. We also urge that health professionals be trained to offer increased support and counseling to *all* families.

It is crucial that members of different professional groups be sensitized to the ways that their colleagues in other professions view the world. The training of any "bridge" person must include knowledge not only of the procedures used in the various professions that are being bridged, but also the institutions in which they are embedded and the professional culture that surrounds them. Some of this can be acquired by exposure to other professionals but the understanding of it that is essential to effective collaboration probably depends on a more explicit examination of it during training.

We will gain little if we establish new bureaucratic structures without careful consideration of the qualities of the people who will make up that structure.

In order to achieve the goals of EPSDT, special resources for developmental review need to be created to supplement the kinds of assessments typically done by physicians. The nature of these special resources primarily are trained personnel. Such personnel should have a very firm grounding in normal child development, should have extensive skills in using developmental evaluation techniques, should know something about the arena in which physicians operate and similarly should have some familiarity with the nature and requirements of effective educational settings. They must also know about parents, about families, their ethnic and economic diversity, and the realities in which they live currently in our society.

### Data Available

It is strongly recommended that there be constructive use made of data already available from past projects such as the

collaborative studies, in order that we may become much more sophisticated about issues of longitudinal prediction.

As has been noted repeatedly in this report, we recommend research and development or demonstration projects to develop measurement standards appropriate to the assessment of young children. There should also be research into methodology of developmental review of young children with emphasis on the variety of assumptions and theories related to age and ethnicity.

There must be the development of strategies for the simultaneous selection of measurement variables and the identification of program needs, for the establishment of research, development an devaluation priorities. There must be an emphasis on the overlap between research and consumer priorities. In addition, there must be provision for taking into account family needs and values in the conceptualization of measurement related problems, and in the development, selection and application of any measurement or other instruments. Parents and those directly responsible for the welfare of the children must be involved in all decision making processes in this area.

The focus in interpretations of assessment must always be on individual differences that will lead to appropriate intervention for each specific child, as opposed to a focus on group differences and comparisons.

Any instruments that are developed must describe capabilities and limitations for which some form of intervention, including parent education, may be prescribed, as opposed to tests or instruments that are interpreted only in normative terms.

There should be developed a multi-measure, multi-domain, multi-function collection of measures from which instruments may be selected at a local level, by local option.

One of the most important issues in evaluation must be the inclusion of a search for possible positive and negative side effects of any system of developmental review on children and their families. This would include an investigation of any problems associated with potential "labeling" as a consequence of the administration of any of the aspects of developmental review herein recommended.

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